

**Developmental Disabilities Council Minutes
Courtyard Marriott, Federal Way
November 18, 2005**

Present

George Walker (Chair), Leo Finnegan, Vickie Foster, Larry Garman, Suzanne Gries, Mike Hatch, Shawn Latham, Alphonso Lee, John Lemus, Sara McQueed, Alicia McRae, Adrian Patayon, Erin Platts, Michael Raymond, Leandro Razo, Laethan Wene, Diana Zottman, Janet Adams (DDD), Marijo Olson (CTED), Sherrie Brown (UAP), Mark Stroh (P&A), Patty McDonald (ADSA), Diana McMaster (MAA), Tabitha Harrison (DOH)

Absent

Bill Anderson, Greg Rodriguez, Lori Flood, Lou Colwell (OSPI), David Kludt (MHD), Kelly Boston (DVR)

Guests

Sue Elliott (Arc of WA), Grier Jewell (Arc of WA), Kary Hyre (Long Term Care Ombudsman), Louise Ryan (Long Term Care Ombudsman Program)

Staff

Ed Holen, Clare Billings, Linda Walling, Eva Rooks, Stephanie Benfield, Cathy Townley, Brian Dahl

Call to Order/Introductions

The meeting was called to order and introductions were made.

Minutes

Motion: Council approve the September 2005 minutes as amended. Mike R. moved and Laethan seconded. The motion carried unanimously.

Adjustments to the Agenda

A few adjustments to the agenda were necessary due to time constraints.

Chair's Remarks

George discussed the oral history book "Becoming a Citizen" that Susan Schwartzenberg presented to the Council earlier this year. The book was created through the UW, and highlights progress families have made in the disability movement.

Each Council member received a copy. Sherrie Brown talked about the press and distribution that is occurring for this book.

Michael Rogers was recognized for his contribution to the Developmental Disabilities Council. Michael has been on loan from DDD and will return to work for them at the end of November. Michael thanked Ed for supporting him to take the lead on the Alliance for Full Participation Summit and in working on accessible taxis.

George reminded the Council of some upcoming events. The second annual Developmental Disabilities Endowment Trust Fund shareholder meeting will be held on November 21, 2005 at the Doubletree Hotel at South Center from 4:00 p.m. until 6:00 p.m. People will be able to visit with the board and hear from the State Investment Board.

The annual King County Legislative Reception is also being held on November 21, 2005 in the same hotel at 7:00 p.m.

Lori Flood is currently the Council representative on the Home Care Quality Authority, but needs to step down. George stated that there is at least another two and a half years left on Lori's term. If any other Council member is interested in serving on that board let Ed know.

Staff passed out ballots for Council members to vote on the second Vice-Chair. Mike Hatch will be the Council's second Vice-Chair.

There has been another article in the Seattle PI about DDD Community Protection clients. In 2001, the Council attempted to pass DD Ombudsman legislation, which would have addressed some of the issues that are now occurring around the abuse of clients in licensed facilities. Ed and Sue Elliott from the Arc of Washington are in the process of co-authoring an Opinion Editorial piece about this issue, including some of the following action steps:

- There should be a way for clients to get out of the Community Protection program.
- Regular training for state employees and contractor staff that have contact with these clients.
- Decrease DDD case manager's caseload.
- A form of third party oversight.
- Funding for adequate wages for staff.
- Enforceable financial accountability for contractors that do not meet standards.

Mark Stroh from Protection and Advocacy added that P&A would take an advocacy position consistent with what Ed outlined.

Executive Director Report

Ed passed out the outcomes from the National Alliance for Full Participation, which he hopes will become the action plan for our state. Leaders in Washington State would like to bring together a similar event in January 2007 that would connect with the Council's annual legislative reception. This team also came up with a policy statement on Medicaid for Washington State.

The "Waiting Game" is another project that will put a face to families on DDD's waiting list. If anyone knows a family on the waiting list for services and would like to be showcased, let Ed know.

Ed discussed a letter from Karen Flippo of the Council's national organization requesting contributions to the Hurricane Katrina Assistance for People with Disabilities Fund. He stated that several other Councils have already contributed. Patty asked if we knew anything about the organization that the money would go through. Ed said that it is an organization like Parent to Parent in our state, and the Council director in Louisiana had stated that this would be the most direct way to donate to people with disabilities impacted by the Hurricane.

Motion: To approve contributing \$5,000 to Families Helping Families in assisting people with developmental disabilities in Louisiana. Mike H. moved and Mike R. seconded. The motion carried unanimously.

Government Management Accountability Performance (GMAP) Report

The GMAP presentation focused on staff activities. Ed reviewed the Council's priority areas, general operations and administration, and the DDLOT performance priority, along with the staff activities in each.

Performance Priority #1: Increasing people engaged in system advocacy. Staff activities include local leadership legislative training, presentation of Council's public policy/legislative agenda at national workshop and hosted monthly legislative strategies group.

Performance Priority #2: Expanding capacity of supports and services. Staff activities include tracking 19 contracts, representing Council at Workforce Investment Grant Steering Committee, State Use Building Committee, Human Services Coalition and DDD Family Support Advisory Committee. Also, provided staff support for DD Residential Advisory Council, follow up to 2005 Alliance for Full Participation, and monitoring of Dan Thompson Land Trust Bill implementation.

Performance Priority #3: Improving quality of services. Staff activities include implementing Informing Families Building Trust project with DDD, Real Choices II Advisory Committee, training volunteers for the Waiver Quality Assurance teams, publishing Core Indicators Report and meeting with media firm on public communications.

For the Informing Families Project, the Arc has helped put together a DVD and a web site that will lay out the basics around the DD system for people new to the system. Council members will receive a DVD when it comes out in January or February.

General Operations and Administration. Staff activities include planning for 2007-2011 state plan, budget and allotment processes, meeting with the governor about Council and DDLOT, attending "Becoming Citizens" book dedication ceremony, attending meetings with the UW Advisory Committee and WPAS.

Additionally, completed and filed 2006 state plan amendment, preparing 2005 annual performance report, conducted discussion with self advocates around the state, attended NADCC conference, board meetings and participated in conference calls, and conducted new Council member orientation.

DDLOT Performance Priority: Building assets for future needs and measured by increased enrollments and private contributions. Staff activities include facilitating governing board meetings, preparing annual trust holders meeting, managing account system, preparing quarterly trust reports, publishing requests for proposals for 2005 tax preparation, managing database system and conducting targeted mailings.

Advocacy Partnership

Sue Elliott and Grier Jewell from The Arc of Washington State presented information on the activities of two DDC grants: the Advocacy Partnership Project and the Self Advocacy Initiative Project.

Sue shared that the Advocacy Partnership Project is a year-round effort to provide the "tools" of effective advocacy to individuals with developmental disabilities and their family members, as well as to coordinate statewide advocacy efforts related to developmental disabilities. She reminded everyone that without the advocacy of parents and individuals with developmental disabilities, we would not have made gains in public policies such as inclusive education and community-based services. It is through advocacy that the DDC's policy priorities are realized, and it's through the support of the DDC that developmental disabilities advocacy is one of the most respected grassroots efforts in Olympia.

In order to help families and individuals have a voice, project staff provide information on issues and the legislative process through presentations, workshops, emails, publications and an online action center. Project staff also provide technical assistance to groups and organizations, such as the Community Advocacy Coalition.

Advocacy Day, held weekly during the legislative session, is a key feature of the project. The strong, consistent presence of individuals with developmental disabilities and their families raises awareness of DD issues and brings home the importance of real citizen involvement in shaping public policy. It's through this ongoing effort to support and coordinate advocacy that the visibility and progress of developmental disabilities programs and policies continues to enjoy success.

Grier shared that the Self Advocacy Initiative Project specifically focuses on building the strength of self-advocacy in Washington State. A fundamental component of the project is the support of Self Advocates in Leadership (SAIL), which successfully worked to introduce and pass legislation related to accessible parking, and which has grown to become a recognized and effective public policy coalition. In addition to supporting SAIL, the project promotes self-advocacy on several levels: from easy to understand information about issues to group advocacy efforts and leadership development. This past year, project staff assisted SAIL members in developing a guide to self-advocacy. The booklet outlines several individuals' success stories related to advocacy from personal to systems. It has been well received and serves as a national model for successful advocacy.

Committee Reports

Public Policy Committee

Diana Z. reported as both Lori F. and Donna P. were at the DD Residential Advisory Council meeting that day. Diana reported that the Committee discussed:

Diana Z, Lori, and Donna's trip to attend the DD Council national public policy Conference in Tennessee.

DDD's working age adult policy

The 2006 legislative conference calls will be on Friday's at noon. The call in number will be distributed to Council members.

The 2006 legislative agenda.

Cecile Lindquist gave a presentation on education reform, the WASL and an update on the Birth to Three bill.

Governance Committee

Suzanne reported that the Committee was bringing forth a motion. To create guidelines to assist in selecting Council members and to approve their travel to conferences and workshops.

Motion: Council approve the Guidelines for Selecting Council members to Attend Conferences/Trainings as written. The motion carried unanimously.

Membership Committee

Vickie reported that the Committee discussed:

Development Day in May and associated travel costs.

Attendance policy was sent forward to Governance committee.

Hotel charges that the Council can't cover: movies, bottled water etc.

Members wanting a mentor should connect either Alphonso or Erin.

In an effort to not have people eat meals alone, there will be a sign up sheet at the front desk of the hotel.

Agency Reports

Division of Developmental Disabilities

Janet presented information on the recent audit by the Centers for Medicare and Medicaid Services (CMS) of the four new DDD waivers. A draft report is expected by January and a final one, which she will share with the DDC, in early Spring. She also gave a brief update on the progress of the DDD Full Assessment and the fact that it will probably be delayed a couple of months in implementation because of the many policy issues that ADSA is wrestling with.

She shared the first results from the "face to face" waiver surveys that Regional QA managers and DDC volunteers are doing and also information on the hours of Medicare Personal Care that case managers are allowing based upon the CARE assessment. Adults have, on the average, seen an approximate 10 hour increase in the amount of hours available while children have seen an average decline in hours available of approximately 14 hours. However, the children's data covers too few months to be able to look at it for trends and patterns.

Janet distributed information on the community protection program. The Seattle PI has been running a series that sensationalizes the program and she wanted people to have the basic facts about the program at the same time.

She also distributed a flyer on the importance of good dental care for people with developmental disabilities.

Dept. of Health

Tabitha reported on the Governor appointed task force, "Caring for Washington Individuals with Autism Task Force," convened for the first time on November 14, 2005. The task force is charged with developing strategies and recommendations to the State Legislature by December 2006 about how to best prevent, identify, treat, and accommodate the needs of individuals with autism and their families. Recommendations to the Legislature will include ways to improve the delivery and coordination of autism services in the state.

The task force will meet monthly from November 2005 until April 2006, with support from DOH staff. More information is available at: www.leg.wa.gov/pub/billinfo/2005-06/htm/bill%20reports/senate%20final/5311.fbr.htm

She shared that the National Association of County and City Health Officials (NACCHO) has issued an Request For Proposal for "Addressing Disability in Local Public Health". NACCHO plans to award \$70,000 to local health departments to 1) plan and implement an innovative means by which to address health promotion of persons with disabilities, and 2) collect preliminary performance and evaluation data on the intervention. Each grantee will be awarded a maximum of \$25,000 for a 12 month project. More information is available at:

www.naccho.org/topics/environmental/documents/DisabilityRFPandapplication001.pdf

Aging and Disability Services Administration

Kary Hyre, State Long-Term Care Ombudsman (LTC) and Louise Ryan Assistant State LTC Ombudsman provided an overview of the LTC Ombudsman Program.

The LTCOP has a basic principle of being "resident directed". Training and complaint work is always at the direction of the resident. The LTCOP philosophy is:

- Maintain and improve understanding that the resident is the "customer" of the licensing authority -- not the provider business.
- Maintain and improve dissemination of the principles of "Resident Centered, Resident Directed Care" and "Individualized Care."

The LTCOP processed over 4000 complaints last year on behalf of 3500 individuals. The program also provides consultations to residents, staff, family and others.

This year they were awarded a Senior Medicare Patrol grant to address fraud and abuse in long-term care settings. This project has just begun and is starting to coordinate with local law enforcement to get serious cases of abuse and neglect prosecuted.

They appreciate the grant provided by the DD Council. The objective of DDC's grant is to train LTC ombudsmen on developmental disabilities in the context of resident rights and living in a long-term care facility. A section on sexual abuse was also included in the curriculum.

Medical Assistance Administration

Diana reported that the Children's Health Program goes into effect January 2006. This two year program is limited by a funding cap. The maximum of 8700 children covers medical for children under 18 years and less than 100% Federal Poverty Level who are not eligible for Medicaid because of citizenship status. MAA anticipates a large waiting list.

Medicare Part D is overwhelming the Medical Assistance 1-800 line. Those on Medicare and Medicaid will pay a co-pay. They are being automatically assigned to a Medicare Part D plan. Medicaid is sending out a client and provider memo.

MAA has several bills sponsored by aging. Most are related to funding and staff increases to cover caseload and Medicaid Management Information System procurement.

Health and Recovery Services Administration is going through a reorganization process.

University Affiliated Program

Sherrie shared that she will be in Southeast Asia for six months working on a children rights law and the juvenile justice system. Mark Harniss from the UW will be taking her place during her absence. His expertise is in assistive technology and assistive cognition.

Protection & Advocacy

Mark Stroh discussed the Community Protection articles that appeared in the Seattle PII and provided status regarding the Allen case, which involves people with developmental disabilities at Western State Hospital.

Division of Vocational Rehabilitation (DVR)

Kelly was unable to attend but had a handout that was passed around.

Mental Health Division (MHD)

David was unable to attend but had a handout that was passed around.

With that the meeting was adjourned.